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SENATE RESOLUTION

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WHEREAS, Rare diseases and disorders are those which affect small patient populations, typically populations smaller than 200,000 individuals in the United States; and

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WHEREAS, Nearly 7,000 rare diseases affect millions of Americans and their families; and

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WHEREAS, Children with rare genetic diseases account for more than half of the population affected by rare diseases in the United States; and

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WHEREAS, Many rare diseases are serious, life-threatening, and lack an effective treatment; and

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WHEREAS, Rare diseases and conditions include epidermolysis bullosa, progeria, sickle cell anemia, Tay-Sachs, cystic fibrosis, many childhood cancers, fibrodysplasia ossificans progressiva, and Williams Syndrome; and

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WHEREAS, People with rare diseases experience challenges that include difficulty in obtaining an accurate diagnosis, limited treatment options, and difficulty finding physicians or treatment centers with expertise in their disease; and

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1 WHEREAS, Great strides have been made in research and
2 treatment for rare diseases as a result of the Orphan Drug Act
3 and other acts of Congress; and

4 WHEREAS, The United States Food and Drug Administration and
5 National Institutes of Health have established special offices
6 to advocate for rare disease research and treatments; and

7 WHEREAS, The National Organization for Rare Disorders, an
8 organization established in 1983 to provide services to, and
9 advocate on behalf of, patients with rare diseases, was a
10 primary force behind the enactment of the Orphan Drug Act and
11 remains a critical public voice for people with rare diseases;
12 and

13 WHEREAS, The National Organization for Rare Disorders
14 sponsors Rare Disease Day nationwide to increase public
15 awareness of rare diseases; and

16 WHEREAS, Rare Disease Day has become a global event
17 occurring annually on the last day of February; and

18 WHEREAS, Rare Disease Day was observed in the United States
19 for the first time on February 28, 2009; and

1 WHEREAS, Rare Disease Day is anticipated to be observed
2 globally in years to come, providing hope and information for
3 rare disease patients around the world; and

4 WHEREAS, It is fitting that the Illinois Senate joins in
5 this global observance and takes part in the fight against rare
6 diseases; therefore, be it

7 RESOLVED, BY THE SENATE OF THE NINETY-EIGHTH GENERAL
8 ASSEMBLY OF THE STATE OF ILLINOIS, that we designate the last
9 day of February in 2013 and 2014 as Rare Disease Day in the
10 State of Illinois; and be it further

11 RESOLVED, That we recognize the importance of improving
12 awareness and encouraging accurate and early diagnosis of rare
13 diseases and disorders; and be it further

14 RESOLVED, That we wholeheartedly support a State,
15 national, and global commitment to improving access to and
16 developing new treatments, diagnostics, and cures for rare
17 diseases and disorders.